

Quality of Life Outcomes For People With Alzheimer's Disease and Related Dementia

Wisconsin Bureau of Aging and Long Term Care Resources
Alzheimer's Demonstration Grant – Administration on Aging, Washington DC

Planning Committee Project Summary as of May 29, 2002

The Dementia Outcomes Advisory Committee was assembled in January of 2002 for the purpose of developing quality of life outcomes for people with Alzheimer's disease and related dementia. The outcomes are intended to be used in the state and county level home and community based long-term care system as standards for publicly funded services.

Advisory Committee members include people from across the state of Wisconsin representing all provider groups (from day and in-home services to assisted living), professions (Nursing, Case Management, Guardianship, Administrators, Direct Care, Policy Developers, Licensing, Clergy, Alzheimer's Assn. Staff, Ombudsman etc.) and demographics (rural to metropolitan). The committee also includes a person in the early stages of Alzheimer's disease and two family caregivers. All committee members have been chosen for their long standing experience and expertise in providing quality dementia care. The project facilitator is a private consultant, expert in outcomes development and implementation.

The committee began meeting in March 2002. After four meetings the eight outcomes statements have been finalized. The group is now in the process of clarifying the specific indicators to be examined for each outcome, specific measures which show evidence that the outcomes and indicators are being met, and related good practice that helps to set the environment for the outcome to occur in. The following draft contains the eight outcome statements and an example of a potential indicator with corresponding observable measures.

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The Eight Outcome Statements*:

Reflecting Quality of Life for the Person with Dementia

As a person with dementia,

I have the best possible physical well-being

I have meaningful relationships

I am involved in life

I experience familiarity

My rights are respected and honored

I am accepted and understood as an individual

I experience hope

“As a person with dementia, I value some of these outcomes more than others. Also, my priorities are different from others who have dementia, and this is noted.”

Related outcome pertaining to caregivers:

I have caregivers who are educated and supported

Sample Outcome Statement, Indicator and Measures*:

Outcome statement:

"As A Person With Dementia, I Have Meaningful Relationships"

Indicator:

I have the opportunity to sustain caring relationships with my family members and extended family as desired

Observable Measures:

Self/caregiver report

Observation

- Interactions
- Conditions
- Observable nurturing contacts w/ family

Records (or interview)

- Visiting hours
- Frequency of contacts with family/friends
- Proximity or access to family/friends
- How often person attends normal family functions

Related Good Practice:

- Participation of family & friends in events person desires and attends
- Transportation available

Note: This is only one of several indicators for this outcome, it is not meant to be all inclusive.

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